Offering Help to Flood Victims

No one knew when it began to rain on June 4, 2008, that the next few days would bring the costliest disaster in the history of Indiana. When the rain stopped, 29 counties had been declared major disaster areas.

As reports began to come into The Arc of Indiana office about individuals with disabilities who had been forced from their homes, we knew that we had to do something. Each year The Arc sets aside funds to provide winter heating assistance to people with disabilities. This year funds were still available, and it was quickly decided that those funds should be re-directed to help flood victims by providing them with a $100 gift card to use as they needed.

One of the 56 people who received assistance was six-year-old Logan Sturgeon. That morning his mother Serena had taken him to basketball camp. He won his first trophy. When camp was finished, they went to spend some time with his grandmother. That’s where they were when Serena got a message from her older son that water was coming into their house. By the time she got the message, phone service was out, and she couldn’t get back to her house. Her daughter was at work, and for some time that afternoon she didn’t know where her two older children were.

Thankfully everyone was safe, and later that night they were reunited. But the first shelter they were sent to flooded, and they had to move. Serena remembers watching the line of people walking to the parking lot to be relocated. Everyone was carrying the few prize possessions they had been able to save. Logan was proudly carrying his trophy.

After a few days the family decided to leave the shelter. Logan has autism, and the other people in the shelter were not very tolerant. Following multiple complaints and discussions with those running the shelter, they moved to a hotel. They soon discovered that it was going to be some time before the family could go home, yet they didn’t have enough money to stay in the hotel. First they moved into a tent with two coolers. And finally they moved into a trailer owned by Serena’s sister.

When the water receded, and they caught their breath, they found themselves homeless—with one television, a kitchen table, a few photos and Logan’s trophy. With the help of both friends and strangers, the family has now moved into a new home, and they are putting their lives back together. The money they received from The Arc was used to purchase cleaning and laundry supplies and gasoline.

Another $100 gift card was sent to Kathy Hounshell. She had gone out to breakfast with her mother Juanita when a neighbor called to tell them that their neighborhood was flooding. Her uncle and sister waded through the water to get clothing and medications. After Kathy and Juanita were able to move into Juanita’s brother’s house, they will be there for 2-3 more months before they can move back into their own home. They were able to save some of the belongings but lost almost all of their furniture.

“Whatever I was doing, I didn’t lose anyone in the flood, and you didn’t lose your whole house, and other people did,” said Juanita. “So I feel like I’m blessed.”

One of the things that Kathy enjoyed doing was sitting at her desk and writing. She not

Indiana Direct Support Professionals Provide Extraordinary Services Through Floods

Article provided by INARF, www.inarf.org

There are heroes, and then there are those unsung heroes who show quiet dedication to their profession and to individuals with disabilities whom they serve. This became much in evidence during the recent storms and their aftermath that recently ravaged south-central Indiana.

Closed roads and declared states of emergency made travel difficult. Evacuations posed special challenges for law enforcement, fire departments and especially for citizens, friends and families of the victims. Serving as a bright spot during all of this were many Direct Support Professionals (DSPs) who went out of their way and showed a commitment that was truly above and beyond the call of duty.

Here are but a few of their stories:
- Matt Haynes of Sycamore Services worked a 14-hour shift the day of the flood, making sure his participants stayed safe and were entertained in their community center building.
- Kayla Boone, an Army Reservist and employee of Mosaic in Terre Haute, realized the state of emergency in Vigo County would severely restrict travel. She left her home dressed in her army gear which allowed her to pass restricted areas and reach a Mosaic group home in need of assistance.
- Kelly Hoffman was diligent in tracking down and securing resources for a DSI client family after flooding destroyed their home and all belongings. She worked to find temporary housing and persuaded their landlord to repair their home so they wouldn’t have to find another place to live. Kelly continues working with the family to ensure their house is a home again.
- Kimberly Lane of Sycamore Services needed to evacuate Martinsville participants to a safe place, but the available Emergency Shelter was not an option; the environment would have assuredly contributed to the ladies’ anxiety. Kim offered her own home, where she and the participants had a successful “girls’ night out.”
- Tally Sowards helped evac-
Hats Off to Stan, Indianapolis Indians Usher

The Arc of Indiana gives a tip of the hat and thanks to Stan Schenher, an usher for the Indianapolis Indians.

Stan went out of his way to make a night at the ballpark memorable for two men who receive services from Achieva, local chapter of The Arc in Wayne, Fayette, Franklin, and Union counties.

Lani Sollenbergim and Mandy Kenworty, direct support professions for Achieva, shared this story with The Arc:

“About a half hour later, Stan let me know that he had spoken to the young lady and that she would do her best to throw shirts in our direction. At the end of the second inning, when shirts are thrown out, Tim caught a shirt and was thrilled. Stan made a point to come to our seats and congratulate Tim on his catch.

“We were unable to catch a T-shirt for Charles, and Stan encouraged me to capture the attention of the first baseman and encourage him to throw us a ball after the third out. Stan noticed that despite my repeated attempts, I was not going to get a ball from the baseman. Stan returned and presented Charles with an Indianapolis Indian’s baseball, and Charles’ name popped up on the center field scoreboard. When Charles returned home to Richmond, his excitement in sharing his night at the ballpark could not be contained because of what Stan did for him.”

In today’s busy world, it is easy to forget that a simple act of kindness can mean so much. Thanks, Stan, for your kindness to Charles and Tim—you made their night at the old ball game.

Mission statements are often composed in a hurry and shelved. The mission statement that Elbert Johns and Stone Belt spent hours parsing and polishing to get just right is something many of us revisit constantly, but the whole community, too, can be measured by the extent to which it has pervaded all our lives.

And as the Internet loomed as a tool to connect and understand which services were available for whom, and what they consisted of, Elbert migrated to TheArcLink.com, the national Web site dedicated to this goal.

Elbert worked tirelessly to make this world more complete and more accessible for those who years ago might have been forgotten and warehoused. Elbert changed the future for these people at the local, state and national level.

But the main thing about Elbert was that he was caring, loving, embracing, encouraging, insistent on justice; but never anything but polite, prepared and positive. He was very active in his church, but always embracing persons with different points of view, cultures and ways of doing things. He was a very loving husband with a remarkable wife, Chris, and four wonderful children. He doted on his grandchildren.

Community profoundly changed by Elbert Johns’ mission

Elbert Johns, a long-time leader and friend of The Arc, passed away in July. Following is a tribute to Elbert by Charlotte Zietlow, former board member and president of Stone Belt Arc; and current board member and former president, The ArcLink Inc.

We believe in the uniqueness, worth and right to self-determination of every individual. Therefore, it is our mission, in partnership with the community, to prepare, empower and support persons with developmental disabilities and their families to participate fully in the life of the community.

In the early 1990s, Elbert Johns, executive director of Stone Belt Arc for nearly 20 years, led the Stone Belt board, the staff and self-advocates in forming this mission statement for the agency. I carry this statement on a little card with me, although I finished 16 years on the board several years ago.

And I am not the only one. For me, and for the community, Elbert Johns brought knowledge and compassion and courageous, stretching leadership to Stone Belt from the early ‘80s. Step by step, year by year, he encouraged, cajoled, empowered all of us to understand the potential of persons with intellectual and other disabilities.

For Elbert, there was no person who was not able to become more than who they were, who could not participate in the community, in his or her own lives, in ways they had not thought they could. That applied not only to the consumers at Stone Belt, but to the staff, the board, the whole community. Elbert did not let us rest.

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“J just wanted to let you know about our wonderful trip to the Indianapolis Indian’s game on August 13. It was a great night for two of the men we serve, Charles Bogan and Tim Patterson. When we arrived at the ballpark, we walked to Section 116 where we were greeted by a gentleman by the name of Stan. Stan had been our usher on the previous game we attended on July 23rd. Stan remembered that at the last game, we caught two T-shirts. I asked Stan if he thought I would be able to catch two more T-shirts for the men we brought with us to watch this game. Stan said he would talk to the girl that throws the shirts, let her know where we were sitting, what we were wearing, and to throw the shirts our way.

“About a half hour later, Stan let me know that he had spoken to the young lady and that she would do her best to throw shirts in our direction. At the end of the second inning, when shirts are thrown out, Tim caught a shirt and was thrilled. Stan made a point to come to our seats and congratulate Tim on his catch.

“We were unable to catch a T-shirt for Charles, and Stan encouraged me to capture the attention of the first baseman and encourage him to throw us a ball after the third out. Stan noticed that despite my repeated attempts, I was not going to get a ball from the baseman. Stan returned and presented Charles with an Indianapolis Indian’s baseball, and Charles’ name popped up on the center field scoreboard. When Charles returned home to Richmond, his excitement in sharing his night at the ballpark could not be contained because of what Stan did for him.”

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Memorial contributions may be made to:
TheArcLink, 320 W. 8th Street, Ste 126, Bloomington, IN 47404, or Trinity Episcopal Church (memo “Capital Campaign”), 111 S. Grant St., Bloomington, IN 47408.
Heroes among us

What heroes we have in our movement! In this issue you have met direct support professionals who, in the midst of the chaos of flash flooding, made sure the folks they support were safe. You met staff that responded quickly with training they had received to save lives. You met an usher at an Indianapolis Indians game who made sure two men from a local Arc chapter had a great night at the ball park.

We count on heroes every day, and they come through more times than not. We should never take them for granted.

When you see someone making that extra effort, thank them. It may not be in times of emergency. It may be as simple as helping someone through a tough moment, taking the time to help with a simple task, or making someone laugh. It may be something that makes a difference you will never see.

The Arc of Indiana will take the opportunity to give our thanks at our Appreciation Luncheon on October 15. We have some amazing people to recognize, and if you want to just smile and help us recognize them, come to Indy for a great day. You will leave realizing we have more heroes than we can ever imagine. This issue also includes comments from people who want your vote, and information on changes and challenges in education and Indiana’s service system. How our state will be lead in the near future, and how services and supports will be available and delivered, depends on you—and the person next to you—caring enough to be involved.

...to one person you may be the world.

My daughter Kesia has a favorite saying on our refrigerator. “To the world you may be just one person, but to one person you may be the world.” Thank you for all you do. And remember, to that person you are the world.

New Albany self-advocate has a knack for inspiring others

Mark Hublar is like many other men his age. He enjoys watching football, he works full-time, and he attends church every Sunday. He’s a music buff and occasionally dons an Elvis costume and performs at events. He builds and paints models of space shuttles.

But when Hublar was born 44 years ago, no one could have predicted he would go on to lead such a fulfilling life. He was born with Down syndrome at a time when few opportunities existed for people with developmental disabilities, in the early days of The Arc and before the existence of the National Down Syndrome Congress.

Hublar, however, has never been one to let his disability prevent him from being a part of society. In junior high, he attended gym and lunch period alongside everyone else in his school, and by the time he graduated from New Albany High School in 1982, he had made a world of new friends.

Down Syndrome Indiana named Hublar the recipient of the Star Award for his achievements in promoting self-advocacy.

Teachers and parents have been supportive of Hublar along the way, especially his father Al, a founding officer and currently treasurer for D.A.D.S. of Southern Indiana—a branch of the non-profit Down Syndrome Support Association of Southern Indiana.

People have taken notice of Mark Hublar’s hard work—especially his natural ability to inspire others. This spring, Down Syndrome of Louisville (Ky.) named Hublar Citizen of the Year. A few months later, Down Syndrome Indiana named Hublar the recipient of the Star Award for his achievements in promoting self-advocacy.

Hublar’s resume is impressive: He’s worked for Rauch Industries, Floyd Memorial Hospital and currently is a full-time greeter for Wal-Mart. He lives by himself in the house he shared with his grandfather for three years prior to his grandfather’s death in 2000. During those years, Hublar helped his grandfather cope with the aftermath of a stroke.

Hublar, who was selected by the National Down Syndrome Congress to appear in a video, “More Alike than Different,” hopes to continue being an advocate. As he told his hometown newspaper, the New Albany News and Tribune, “I’m proud to have Down syndrome so I can be a spokesperson for others.”

To see Mark Hublar in the “More Alike than Different” video, go to: www.ndsccenter.org/morealike/campaign.php

Red Cross Recognizes KCARC Employees for Lifesaving Actions

Employees of KCARC, local chapter of The Arc in Knox County, have been recognized by the Old Northwest Territory Chapter American Red Cross for Extraordinary Personal Action.

Robert Uhlik used American Red Cross lifesaving skills at a Special Olympics bowling event in Indianapolis to save the life of an athlete who was choking on a piece of food. To dislodge the food and restore the athlete’s breathing, Uhlik used the Red Cross CPR and first aid training he received at KCARC.

Lacee Holt was working at a group home when one of the residents began choking while eating dinner. Lacee called 911 and, again, using training she received at KCARC, Lacee was able to dislodge the food. By the time an ambulance arrived, the resident was fine and did not need to go to the hospital.

The Arc of Indiana congratulates Robert, Lacee, and KCARC for their training and quick action that saved two lives.
**INDIANA ADULT GUARDIANSHIP SERVICES PROJECT OFFERS HOPE OF GOOD THINGS TO COME**

![Image of a group of people]

**The mission of the project is to improve the quality and availability of guardianship services for adults ages 18 and older.**

The successful SSFHS Volunteer Advocates for Seniors Program and Northwest Indiana Adult Guardianship Services, Inc. are working with the project to develop best practices.

**Additional project goals include:**
- Conducting research and review of Indiana and national guardianship demographics, statutes and recommended best practices.
- Sponsoring the 2008 Northwest Indiana Regional Adult Guardianship Services Symposium (December 5, 2008) and a 2009 Indiana Adult Guardianship Services Symposium (April 2009).
- Envisioning what might be

**The Arc of Tomorrow**

As The Arc of Indiana moved past its 50th anniversary, staff and board members considered, “What do we want The Arc of tomorrow to be, both at the state and local level look like—where should we be going from here?”

From this question, The Arc of Indiana has launched a two-year effort to develop new ways for The Arc of Indiana and local chapters of The Arc to operate. Areas being explored include membership, participation in statewide and public policy activities, outreach efforts in the community, family support activities and self-advocacy. Different models for involvement will be tested and shared with other chapters.

The effort will also include engaging related organizations such as Indiana Special Olympics, Best Buddies, Indiana Down Syndrome Foundation, UCP, ASK, IN-SOURCE and others in this effort.

The ultimate goal of The Arc of Tomorrow is to develop a concrete vision of what we should be in conjunction with our chapters and begin implementing The Arc of Tomorrow in a conscious effort to be what we believe we should be.

**The journey towards The Arc of Tomorrow has begun, and we are looking forward to where it will take us.**
Meet the Candidates

Candidates for Governor Weigh in on Issues Impacting People with Disabilities

Jill Long Thompson

Do you have a loved one in your immediate or extended family who has a cognitive or other developmental disability?

Yes

On a scale of 1-10, with 1 being the lowest and 10 being the highest, how would you rank your knowledge of issues facing people with cognitive and other developmental disabilities?

Seven

The federal Individuals with Disabilities Education Act (IDEA), passed in 1975, guarantees all children the right to a free and appropriate public education in the same school they would attend if they did not have a disability. In Indiana, parents and students with disabilities continue to face obstacles in accessing the tools they need to gain the necessary education to have a more meaningful career and life.

Do you have a policy statement on education?

Yes

Mitch Daniels

Do you have a loved one in your immediate or extended family who has a cognitive or other developmental disability?

Did not respond

On a scale of 1-10, with 1 being the lowest and 10 being the highest, how would you rank your knowledge of issues facing people with cognitive and other developmental disabilities?

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Do you have a policy statement on education?

Yes
Jill Long Thompson

If yes, does it include statements regarding students with cognitive and developmental disabilities?
Yes

What would you do to improve the quality of educational services for students with cognitive and other developmental disabilities?

- We have an obligation in Indiana to educate every student to help them achieve at the level they are able and in the most appropriate environment. As Governor, I will work with the Department of Education to improve education, to improve teacher professional development and support, and with our state universities to address the shortage of special education teachers to improve the quality and availability of educational services for students with cognitive and other developmental disabilities.

What is your opinion of the federal No Child Left Behind initiative as it relates to students with cognitive and other developmental disabilities?

- As a former member of congress, I will be a leader in reforming No Child Left Behind at the federal level. Working with members of our congressional delegation and former colleagues, I will fight to add flexibility to NCLB. The standardized approach to education is not working.

Indiana closed its last state institution in 2007. Home and Community Based Services are the preferred living arrangements of people with cognitive and other developmental disabilities and their families. Currently about 10,000 people receive services through a Medicaid Waiver, but over 17,000 people continue to wait for services.

What would you do to increase access to services to people with cognitive and other developmental disabilities?

- Indiana needs improvement in our home and community based services network to ensure that individuals can be served close to home in most appropriate setting.

   I am open to exploring the implementation of the “Cash & Counseling” concept to permit more aged and disabled individuals to direct their own home and community based care.

What role do you believe the state should have in providing services to people with cognitive and other developmental disabilities?

- I believe society has a shared responsibility to look after citizens most in need. I fully support state funding for early intervention, and public education for children with developmental disabilities.

   I fully support community based education and life skills training, employment services, and independent living support for adults with developmental disabilities.

   The State of Indiana is experiencing a shortage of people who choose to provide services to someone with a cognitive or other developmental disability as a career path. What can the state do to attract more qualified people to this career path?

   - Many areas in the health care field, including disability services, have workforce shortages, both in the number of trained employees and in the geographic distribution of services.

   I believe we should explore the possibility of loan forgiveness for medical and nursing students who practice in underserved services and geographic areas, and work to address health care workforce shortages through Indiana’s vocational education program and our community college system.

   Many people with cognitive and other developmental disabilities want to work in the community. They can perform many important

Mitch Daniels

If yes, does it include statements regarding students with cognitive and developmental disabilities?
No

What would you do to improve the quality of educational services for students with cognitive and other developmental disabilities?

- My goal is to improve the quality of teaching for all Hoosier students, but I believe that special attention must be paid to the preparation of teachers who work with students with cognitive and developmental disabilities.

Unfortunately, Indiana got its worst rating from a national review group called the National Commission on Teacher Quality (in a very poor overall evaluation) for its preparation of special education teachers. I will work with the new superintendent of public instruction to strengthen teacher standards, improve curricular offerings, and otherwise enhance teacher preparation in Indiana, including special education teachers.

   My appointees to the state Board of Education recently voted to revise Indiana’s special education regulations, known as Article 7, making a number of common-sense changes and revisions to rules that had not been examined or amended for a number of years.

   For instance, the rules previously required that preschool special education students receive 12.5 hours of services, regardless of whether they really needed 2 hours or 20 hours. The new version eliminates the arbitrary 12.5 hour requirement so that students can get the number of hours they actually need.

   The Board’s changes should free up special education teachers from burdensome administrative requirements so that they can spend more time working with students.

What is your opinion of the federal No Child Left Behind initiative as it relates to students with cognitive and other developmental disabilities?

- While everyone who works with NCLB would suggest a number of changes and improvements to the law, it does one very important thing that should not be changed. It demands for the first time that schools report on how well they are doing in getting all students to reach state-set proficiency goals.

   This information is valuable to all education stakeholders, including parents of children with cognitive and other developmental disabilities.

   NCLB currently provides that a certain percentage of students who are severely disabled do not have to take state tests that determine AYP placements. This system, like many parts of the law, is not perfect, but does allow some students to be exempted from state testing for school accountability purposes.

Indiana closed its last state institution in 2007. Home and Community Based Services are the preferred living arrangements of people with cognitive and other developmental disabilities and their families. Currently about 10,000 people receive services through a Medicaid Waiver, but over 17,000 people continue to wait for services.

What would you do to increase access to services to people with cognitive and other developmental disabilities?

- In August 2006, I announced the first significant waiting list reduction in over four years. Since that time, we have brought over 1,200 new people into services, and will bring another 2,000 into services by the end of the current fiscal year.

   We did this without an increase in the budget. Instead, we worked to redesign the way we manage the developmental disability system and
What would you do to increase employment of people with cognitive and other developmental disabilities?

• As a former board member of the National Industries for the Blind, a national organization dedicated to enhancing opportunities for economic and personal independence for those who are blind, I have been a strong advocate for employment opportunities for individuals with disabilities.

I would explore the possibility of offering tax credits to employers to increase employment of people with cognitive and other developmental disabilities, as well as seeking public-private partnerships to boost employment.

Most importantly, I believe the state should lead by example in the employment of individuals with developmental disabilities, providing opportunities for employment within state government.

Indiana has an early intervention program for infants and toddlers with disabilities or at risk of disability known as First Steps. It provides critical services to children 0-3 years of age, at a monthly cost to parents depending on their income. Scientific evidence proves that early intervention is key in helping children who struggle with basic skills. However, in recent years, we have seen an alarming decrease in the number of children being served by First Steps.

What would you do to make sure First Steps is adequately accessible and utilized by families, ensuring services are provided as early as possible to a child?

• In the past, Indiana had a premier program in First Steps to provide early intervention services for infants and toddlers with disabilities or at risk of disability.

In recent years, there has been a decrease in the number of children being served due to changes in eligibility for the program. It should be our goal to reach as many children in need of early intervention as possible to have a positive impact upon their development.

As Governor, I will work with community advocates to help reach that goal.

Health insurance remains a critical issue for families and individuals in Indiana. Indiana has thousands of people without any health insurance. While people with cognitive and other developmental disabilities may have health insurance, it may not cover critical therapies and services.

What is your position on health insurance mandates and why?

• I support mandates that would provide coverage for some services not included in insurance plans because the opportunity for comprehensive coverage for all Hoosiers should be available, particularly when these services can have a profound impact on the life of the insured.

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What is your plan to reduce the number of people without health insurance?

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The State of Indiana is experiencing a shortage of people who choose to provide services to someone with a cognitive or other developmental disability as a career path. What can the state do to attract more qualified people to this career path?

• Since August of 2006, we brought over 1,200 new people into services and have not yet seen consistent evidence of a Direct Service Professional (DSP) shortage in Indiana. We recognize that there is a growing DSP shortage nationally, and that we may see this develop in Indiana as we continue to bring new people into services.

We are getting ahead of the curve on this in two ways. First, we are creating a career path for DSPs through a joint training program with Ivy Tech called INTRAIN. DSPs who complete a two-year curriculum at Ivy Tech will earn
You can check your voter registration and polling location by visiting: www.indianavoters.com or call 1-866-IN-1-VOTE.

For more information, including obtaining a voter registration form, go to: www.in.gov/sos/elections

Exercise Your Right to Vote!

To vote on November 4 you must be registered to vote by October 6, 2008. You must also have a government-issued photo ID to cast your ballot in November.

You can check your voter registration and polling location by visiting: www.indianavoters.com or call 1-866-IN-1-VOTE.

For more information, including obtaining a voter registration form, go to: www.in.gov/sos/elections

MITCH DANIELS

Many people with cognitive and other developmental disabilities want to work in the community. They can perform many important jobs that people without disabilities perform. However, 76% of people with developmental disabilities are unemployed.

What would you do to increase employment of people with cognitive and other developmental disabilities?

• In 2006, the Division of Disability and Rehabilitative Services (DDRS) adopted “Work First” as a key goal in its “Vision 2010” approach to remaking the developmental disability system. We have made significant strides toward achieving that goal.

Over the past four years, successful employment of people with developmental disabilities through Vocational Rehabilitation (VR) has increased by over 23%. Earlier this year, FSSA Secretary Mitch Roob announced new employment initiatives with Community Hospitals in Indianapolis and Lutheran Hospital in Fort Wayne.

To ensure enhanced access to VR, we have funded a series of successful outreach programs, including a minority outreach contract with The Arc. Perhaps the most important change, though, is in attitude and perspective.

In years past, many people with developmental disabilities were told that they were “too disabled” to work. We have rejected that view. People with disabilities can compete successfully in the workplace. This new attitude is showing results.

Indiana has an early intervention program for infants and toddlers with disabilities or at risk of disability known as First Steps. It provides critical services to children 0-3 years of age, at a monthly cost to parents depending on their income. Scientific evidence proves that early intervention is key in helping children who struggle with basic skills. However, in recent years, we have seen an alarming decrease in the number of children being served by First Steps.

What would you do to make sure First Steps is adequately accessible and utilized by families, ensuring services are provided as early as possible to a child?

• First Steps serves children with developmental delays and disabilities from birth to age three. As we look to the future, we are anticipating increases in children with diagnosed disabilities, not just delays. Of greatest concern is the increase in autism diagnoses.

The Centers for Disease Control (CDC) currently estimates the prevalence of autism in 8 year old children at 1 in 150, and that number is expected to change to reflect a continually increasing prevalence identified at younger and younger ages.

While relatively few children are now diagnosed in infancy with Autism Spectrum Disorders, we believe we are already seeing this impact on First Steps, which pays for assessment and evaluations for developmental delays and which has been seeing increases in those services for the past several months.

While these additional evaluations have not resulted in a one-to-one increase as not every child evaluated is eligible, it certainly indicates that parents and physicians are aware of the program.

In 2006, after an extensive stakeholder review, legislative changes to eligibility criteria were enacted. The intent of the changes was to ensure that First Steps services would continue to be available for all eligible children, particularly for those with the most intensive delays and disabilities.

In discussions with stakeholders and legislators, it was estimated that the new criteria would reduce child counts by 15%. To date, we have seen roughly a 10% decrease in the number of children served statewide—5% less than anticipated.

As we look to the future, Indiana must be prepared for increasing numbers of children needing services of all kinds.

Health insurance remains a critical issue for families and individuals in Indiana. Indiana has thousands of people without any health insurance. While people with cognitive and other developmental disabilities may have health insurance, it may not cover critical therapies and services.

What is your position on health insurance mandates and why?

• Mandates increase the cost of health insurance, which in turn increases the number of people who are uninsured.

What is your plan to reduce the number of people without health insurance and making health insurance affordable and accessible to all?

• For far too many working Hoosiers, health insurance is simply unaffordable. That’s why in 2006, I announced a plan to offer affordable health insurance to the thousands of uninsured in our state.

Together, with the help of the Indiana General Assembly, the Healthy Indiana Plan (HIP) became a reality and will be able to cover nearly 130,000 Hoosiers. HIP is an affordable health insurance plan for uninsured adults between the ages of 19-64 living below 200% of the federal poverty level (FPL).

The program offers comprehensive coverage that includes doctor visits, hospital services, mental health services and prescription drugs. HIP requires every participant to make a modest financial contribution towards their healthcare— between 2% and 5% of gross income. Every participant is given a Personal Wellness and Responsibility (POWER) Account that they must manage which holds their monthly contributions.

HIP is also available for purchase without a state subsidy for individuals above the income thresholds, thus creating an affordable option for even more uninsured Hoosiers. Since January 2008 over 17,000 Hoosiers now have the peace of mind of health insurance.

We also increased SCHIP coverage to cover up to 300% of the FPL for children.
**Information and Resources on New Article 7—Special Education Regulation**

Indiana’s new special education regulations, known as Article 7, went into effect on August 13. This new regulation makes significant changes to many issues impacting children receiving special education.

The Arc of Indiana’s web site includes links to detailed information about the new Article 7, as well as resources for families seeking help.

The Arc of Indiana’s web site, [www.arcind.org](http://www.arcind.org), includes links to detailed information about the new Article 7.

Go to: [www.arcind.org](http://www.arcind.org), click on “State and Federal Programs,” and then click on “Special Education.”

Other sources of information include:

- **Family Voices**
  - [http://fvindiana.blogspot.com](http://fvindiana.blogspot.com)
  - Shares advocacy opportunities and updated information on issues that impact families of children with disabilities or special needs.

- **IN*Source**
  - (800) 332-4433
  - [www.insource.org](http://www.insource.org)
  - Provides training on Article 7, and has statewide regional staff available to provide support and information to parents regarding Special Education regulations and process.

- **ASK**
  - 1-800-964-4746
  - [www.aboutspecialkids.org](http://www.aboutspecialkids.org)
  - Provides training on Article 7, and has staff throughout the state of Indiana to answer questions and provide support, information and resources.

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**OASIS Implementation Moved to January 1, 2009**

The statewide implementation of OASIS, the new system to allocate resources to people on the Developmental Disabilities, Autism and Support Services Medicaid Waivers, has been moved to January 1, 2009. Implementation is being delayed to provide time for consumers and families to plan for the new system, and to allow more time to assure the various components of the program work correctly.

The goal of OASIS is to provide a consistent and appropriate budget system that is directly related to the individual needs and living situation of those receiving Medicaid waiver services.

The current plan calls for persons who have an anniversary date of January 1, 2009 to receive their budget allocation in October, 2008; and for those individuals to then have the opportunity to plan what services and supports they wish to purchase with that budget.

OASIS will touch every person on the three waivers, but will particularly impact those on the Developmental Disabilities and Autism Waivers. It is not yet clear how allocations will compare to current budgets, nor is it clear how changes in budgets will be addressed.

Watch The Arc of Indiana’s web site, [www.arcind.org](http://www.arcind.org), for updates and information.

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**PROGRESS CONTINUES: MOVING PEOPLE ONTO MEDICAID WAIVERS**

Progress continues to move people with developmental disabilities onto the Developmental Disability, Autism, and Support Services Medicaid Waivers. Waivers allow home and community based services to be funded by Medicaid.

Between September, 2006 and August 4, 2008, 2557 people were targeted to receive services; 2521 met with their case manager to begin developing a plan for services; and 2139 had a Medicaid waiver budget submitted for approval. This means over 2000 people since September, 2006 began receiving services, or will soon begin receiving services.

In total, 10,734 people now receive Medicaid Waiver Services through the DD, Autism and Support Services Medicaid Waivers.

3877 people live in ICFs/MR (group homes and large facilities for people with developmental disabilities); 2900 receive state funded services; 1641 are in nursing facilities; and 133 live in state mental health hospitals. 17,897 people remain on waiting lists.

Following is information on the number of people served for each Medicaid waiver.

**Developmental Disabilities Waiver**

<table>
<thead>
<tr>
<th>Targeted to Receive Services</th>
<th>Budget for Services Submitted for Approval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Moving off Waiting List</strong></td>
<td>520</td>
</tr>
<tr>
<td>Emergency / Crisis Situation</td>
<td>283</td>
</tr>
<tr>
<td>Parent Over Age 80</td>
<td>166</td>
</tr>
<tr>
<td>Graduate of Special Education</td>
<td>4</td>
</tr>
<tr>
<td>Moving Out of Nursing Home</td>
<td>88</td>
</tr>
<tr>
<td>Moving Out of State Mental Health Inst.</td>
<td>38</td>
</tr>
<tr>
<td>Moving from State Funded Services</td>
<td>207</td>
</tr>
<tr>
<td>Aging Out of Children’s Services</td>
<td>38</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1349</td>
</tr>
<tr>
<td><strong>Autism Waiver</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Support Services Waiver</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Grand Total All Waivers</strong></td>
<td>2557</td>
</tr>
</tbody>
</table>

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2008 Legislative Interim Study Committees

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During the summer and fall of 2008, legislators are participating in 36 different interim study committees. The Arc of Indiana is monitoring the following interim committees:

**MR/DD Commission**

The MR/DD Commission reviews and makes recommendations regarding the implementation of Indiana’s comprehensive plan for people with developmental disabilities, commonly referred to as the 317 Plan. It also makes recommendations regarding the development of a statewide plan for quality assurance in community-based services; and reviews Indiana’s First Steps, early intervention program for infants and toddlers with disabilities.

The first meeting of the Commission focused on the Objective Assessment System for Individualized Supports (OASIS), and an update from Peter Bisbecos, Director of the Division of Disability and Rehabilitation Services.

**Autism Commission**

The Autism Commission studies the service delivery system for people with autism and their families, including the number of Indiana citizens believed to have autism; funding amounts and sources; expenditures and services provided; the number of clients served; residential options; the need for and effectiveness of programs; and the development of a comprehensive plan for services for people of all ages with autism.

The first meeting of the Commission was held in mid-August. Reports were provided by Peter Bisbecos, Director of DDRS; Dr. Cathy Pratt, Indiana Resource Center on Autism; and Susan Pieples, President of the Board for the Autism Society of Indiana.

The second meeting of the Autism Commission will focus on applied behavior analysis, first responder training in autism and legislative recommendations.

**Health Finance Commission**

The Health Finance Commission reviews and makes recommendations on issues related to home health care workers and reviews trends and incentives to encourage people to enroll in long term care insurance.

The first meeting of the Commission focused on long term care insurance and wages, and benefits and working conditions of in-home care workers.

**Select Joint Commission on Medicaid Oversight**

The Joint Commission on Medicaid Oversight oversees Indiana’s Medicaid managed care system. Two meetings have been held, and the third meeting will take place in mid-September.

**Commission on Mental Health**

The Commission on Mental Health oversees the funding system for managed care providers of mental health services; mental health services delivered by community managed care providers and state operated hospitals; the implementation of managed care programs for people with mental illness that may receive state funds; and studies the unmet need for public supported mental health services.

The Commission has held one meeting and will continue to meet in September.

**Interim Study Committee on Education Matters**

The Interim Study Committee on Education matters reviews and makes recommendations on a wide range of issues regarding virtual learning; and develops recommendations on a funding formula for state funding of school transportation costs. It will also study college readiness; high school athlete steroid testing; and establishing a continuing competitive state grants to.

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The Committee’s first meeting focused on student athlete steroid testing and the Indiana Technology Fund. The next meeting will be held in mid-September.

For more information on Interim Study Committees, go to: www.in.gov/legislative/interim

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You see it in movies, tell jokes about it with your friends and watch it on television, but the word retard isn’t funny. Just like the “n-word,” the “r-word” is offensive and derogatory to people with intellectual disabilities.

“It makes me sad and disappointed to hear people use that word. Even if they aren’t saying it about a person, it’s still hurtful.”

— Mary, a person with an intellectual disability

Three percent of the world’s population has an intellectual disability, making it the largest disability population in the world.
When I think of Brent, I think of music. He loved music, especially the Beatles. One song Brent liked was Garden Party, by Ricky Nelson. The chorus says, “It’s all right now, I learned my lesson well. See you can’t please everyone, so you got to please yourself.” That is something Brent did. Most of us worry about what others will think. I don’t recall Brent spending much time on that fruitless way of thinking. He stayed true to his own ideals.

Trivia and remembering

In every family each individual has a part or a role to play—something for which they can be counted on. In our family, Brent could be counted on for trivia and remembering. He could tell you the make and model of the car that just went speeding past. If a song came on the radio, he would tell you with precision what it was. If a song came on the radio, he would tell you with precision what it was. Brent was such a blow. Again Brent was determined to get better. Again there were hundreds of people praying—many who had never even met him.

Brent loved and was loved

When we knew that Brent would soon be leaving us, my son Alex wanted to know what would happen to Brent when he went to heaven. I told my son that Brent’s spirit will go to heaven, and he will become the infinite perfection that he was born to be. He will have shed his body, which is just a vessel for his soul—a body that held him back at times, and in the end failed, and is no longer needed.

Brent was a part of every family celebration—every graduation, wedding, birth, family reunion and family vacation. He held jobs that he loved and took pride in. He traveled and participated in bowling and Special Olympics. Brent drove go-karts, had girlfriend, went to dances, rode in a limousine, attended a rock concert and had his poetry published. Brent loved, and was loved.

So, while I am terribly sad for myself and for all who knew and loved Brent, I am happy. I am happy for my brother, and I celebrate the good life that he lived and the difference he made in this world.

Poems by Brent Lee Barton


This old house is still standing, the windows are broken and the paint is cracked and dry.

The door was open and I went inside to take a look around. No lights, no sound, dust balls are in the halls. No pictures on the walls, The rooms are bare, no one is there.

Close your eyes and open your mind to God and let him know what you’re thinking.

Amen

The Arc of Indiana Master Trust

Indianapolis Special Needs Trust
Celebrating twenty years of service to Hoosiers and families with disabilities.

Established in 1988, Trust I is now helping over 900 families provide for the future of their loved ones. Trust I investments total over $25 million.

Trust II, established in 1995, allows people with disabilities to fund their own trust, and now serves over 770 people, with $6 million on deposit.

The Arc of Indiana Master Trust

Time-tested, reliable, dedicated
Established by Indiana’s leading advocates for people with disabilities and their families.

For information, call 1-800-392-9100, or visit us at: www.arcind.org

Trust funds are invested and deposited with The National Bank of Indianapolis.
Dancing with The Arc

Thanks to Easter Seals Arc of Northeast Indiana’s dance program, “Dancing with ESArc,” 23 Special Olympics athletes competed in the country’s first Special Olympic Ballroom Dance competition in Fort Wayne on July 5th and 6th.

Steve Hinkle, Executive Director, Easter Seals Arc (and quite a dancer himself) spearheaded the development of the dance program. “Interest has been growing locally and nationally about ballroom dancing. The nature of this competition is truly evidence of the positive impact that dancing has, and proves that it is indeed a universal language.

“With each step, our Special Olympics athletes, volunteer dancers, and Fort Wayne have embraced ‘Dancing with ESArc,’” Hinkle said.

Hinkle hopes the local program will become a model for a new national Special Olympics sport.

Support The Arc of Indiana while you shop for Christmas!

From November 19 to December 3
The Arc will sponsor an on-line auction.
Watch our web-site at www.arcind.org for more details in the coming weeks!